

# Family and Child with Central Nervous System Lesion

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## ABSTRACT

*The aim of the study was to assess if mothers of children with severe forms of cerebral motor impairment perceive their family strength differently than mothers of children with moderate forms of this disorder, as compared. The study included 135 children with cerebral motor impairment. Children were divided into two groups according to the clinical picture severity and their development was followed-up over a one-year period. The course of rehabilitation was assessed by the method of locomotor system functional evaluation. After 12-month rehabilitation, the method of targeted structured interview with the mothers was used. The mothers filled out a questionnaire on family strength, which consisted of 12 questions on their perception of family strength. The present study confirmed the need and efficacy of rehabilitation treatment in children with motor development abnormalities. Study results showed no significant differences in the values obtained by the family strength questionnaire, indicating that there was no statistically significant difference between the two groups in their coping with stressors. It is postulated that the family crisis induced by the birth of a child with risk symptoms must have brought the parents closer and reinforced the family as a whole, irrespective of the severity of the child's clinical picture.*

**Key words:** cerebral motor impairment, rehabilitation, family strength

## Introduction

Family is the first social environment for the child, and mother is the first person the child meets while also filling the child's basic physiological needs. With time, the child meets other family members. Harmonious family relationships make one of the basic preconditions for the normal child's development. Such a relationship is of utmost importance for a child with developmental abnormalities; however, a child's handicap brings a new situation in the family<sup>1</sup>. In spite of great advances in current medicine, developmental disorders in children are encountered daily<sup>2</sup>.

Advances made in neonatal intensive care have significantly improved survival rates in risk and high-risk newborns. Pregnancies that would have been considered unsustainable several decades ago are now initiated and maintained. Infants with birth weight below 1000 g and gestational age less than 28 weeks survive. This in turn entails an increasing number of children with multiple risk factors; there are ever more children with risk symp-

toms and clinical signs of central nervous system (CNS) lesion<sup>3</sup>. Infants born with risk factors carry an increased risk of developmental disorders. Although most of these children will be healthy, the risk of developmental disabilities is increased<sup>4</sup>.

The forms of developmental motor disorders due to CNS lesions are classified into two main groups: cerebral palsy and motor skills disorder<sup>5</sup>.

Cerebral palsy is defined as an umbrella term covering a group of nonprogressive but frequently changing syndromes of motor lesions, secondary lesions or cerebral anomalies that occur in early stages of development<sup>6</sup>. The prevalence of cerebral palsy in schoolchildren is about 2‰ of live births, varying among industrialized countries<sup>7,8</sup> and being much greater in developing countries (8). Now, the diagnosis of cerebral palsy in the first months of life is only made if there are major CNS malformations and in cases where the clinical picture of the lesion has fully developed<sup>9</sup>.

Although cerebral palsy is a chronic disease with very modest therapeutic success achievable, development of the clinical picture of cerebral palsy can be prevented in children with CNS lesions by timely and appropriate rehabilitation of the child with risk symptoms or with cerebral motor impairment (CMI). The diagnosis of CMI is based on the evidence of risk symptoms with a characteristic pattern (e.g., tetraparetic, paraparetic, etc.).

The birth of a child is always associated with changes in the family. The child is a new family member that is unknown to the parents and parents to the child, thus it takes time for them all to adapt to the new situation. This is even more pronounced if some deviation from normal motor development is present in the child.

In 1963, Herbert Otto wrote: »Although professional literature offers data on the criteria identifying »problematic families« and criteria used in the diagnosis of family problems or family disorganization, little is known about how to identify a »strong family«<sup>10</sup>.

When the child suffers from a developmental disorder, the parents have to face the problem, which certainly challenges the family strength.

When talking about stress, we usually focus on the individual, on the way it influences his life and the ways of his coping with stress. However, when talking about family stress, we have to focus on the entire family and its ability to cope with stress. The way of the family's perceiving the birth of a child with CNS lesion will significantly influence the severity of the stress the family have to face with.

The family can reduce the impact of stress situations by reinforcing the family strength. The family can learn how to communicate with each other, to encourage family members to listen, to be able to accept the others' feelings, concerns and ideas. Family members should have a feeling to be loved and respected by other family members. Mc Cubbin and Patterson think that families successfully coping with stress are characterized by the following features: they do things as a family, build self-confidence and trust in other family members, develop social support within the community, enjoy the way of life they have chosen, and develop ways of diminishing stress<sup>11</sup>.

The aim of the present study was to investigate how the family manages the problem of having a child with developmental disorder due to CNS lesion, and to assess the strength of such families.

## Subjects and Methods

The study included 135 children divided into two groups according to the clinical picture severity. Group 1 included 27 male and 40 female children with moderate forms of CMI, score 30–39 on the locomotor system functional evaluation. In these children, abnormalities of motor development need not manifest from neonatal age. Group 2 included 33 male and 35 female children with score 20–29 obtained on the locomotor system functional evaluation, i.e. with severe forms of CMI where abnor-

malities of motor development are evident from neonatal age.

The children were followed-up at Professor M. Stojčević Polovina Polyclinic for Physical Medicine and Rehabilitation in Zagreb every three to four weeks. Parents received instructions on how to perform specific exercises and were advised to practice them at home, for at least three hours a day, along with specific 24-hour care. Exercises were performed according to the child's developmental stage within the diagnosis, according to the method of Vojta and Bobath. Method of Vojta is based on the reflex locomotion. It is a reciprocal activity of global character. Exercises according Vojta were performed three or four times every day. Method of Bobath emphasizes the need for the person's own more effective activity and repetition for learning. Parents are trained in ways to assist their child to achieve best performance.

On the first follow up visit scheduled at 12 months of rehabilitation, locomotor development was assessed and quantitatively evaluated using the method of functional locomotor system evaluation. The method is based on the evidence of risk symptoms classified in a set of 10 criteria as follows: General impression on the child's locomotor performance; Posture and attitude in supine position; Posture and attitude in antigravity position; Assessment of the child's active mobility; Assessment of the child's passive mobility; Assessment of muscle tone; Specific reactions of the child; Postural reflexes; and Development retardation. Each criterion is scored 1 to 5; total score 40–49 denotes mild, 30–39 moderate, 20–29 severe, and 10–19 very severe deviation from normal. Functional evaluation of the locomotor system has been developed by Stojčević Polovina<sup>12</sup>.

After 12-month rehabilitation, the method of targeted structured interview with the mothers was used. The mothers filled out a questionnaire on family strength<sup>13</sup>, which consisted of 12 questions on their perception of family strength<sup>10</sup> (Appendix 1). Answers to the questions are ranged from 1 to 5, indicating: 1 = I disagree; 2 = I partially disagree; 3 = I neither agree nor disagree; 4 = I partially agree; and 5 = I agree.

## Statistics

The results obtained were processed by use of the following statistical methods: descriptive statistics to analyze distribution of the study variables;  $\chi^2$ -test to analyze differences in quantitative variables; Kolmogorov-Smirnov test to test normality of distribution of quantitative variables; non-parametric Mann-Whitney test and Kruskal-Wallis ANOVA to analyze differences in quantitative variables; and Spearman correlation coefficient to calculate correlations among quantitative variables.

## Results

The study included 135 children, mean age at the diagnosis of cerebral disorder 6.77 months, age range 1–48 months. The mean age at initiating rehabilitation was

7.41 months, age range 1–48 months. Maternal mean age  $\pm$  standard deviation (SD) was  $31.91 \pm 1.96$  years. Paternal mean age  $\pm$  SD was  $34.23 \pm 1.96$  years. The number of children *per* family varied from one to five, mean 1.71. The parents with elementary and high school education prevailed over those with university degree.

At 12 months of rehabilitation, improvement of motor development was recorded in the children (Fig. 1).

Differences in the condition distribution before and after treatment yielded by Stuart-Maxwell test were statistically significant ( $\chi^2=77.558$ ;  $df=3$ ;  $p<0.001$ ). After rehabilitation treatment, improvement of the condition was recorded in 86 children, unchanged condition in 48 children, and progression from moderate to severe CMI in only one child. Of 67 children with initially moderate CMI, 41 children had normal findings, ten children showed mild CMI, and 15 children remained in the same category at the end of 12-month rehabilitation period. Of 68 children with initially severe CMI, improvement was recorded in 35 children, whereas 33 children failed to im-

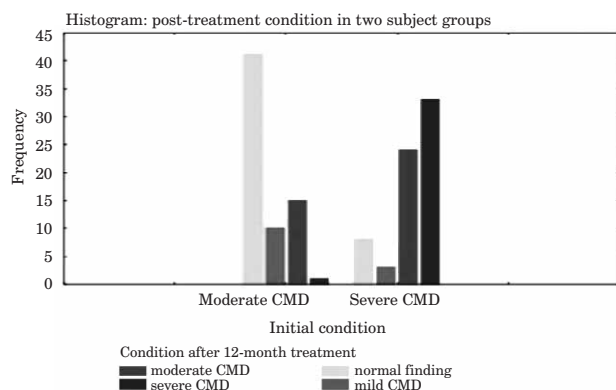


Fig. 1. Motor performance in children after 12-month rehabilitation for cerebral motor disability (CMD).

**TABLE 1**  
EVALUATION OF MOTOR DEVELOPMENT AFTER 12-MONTH REHABILITATION

Cerebral motor disability	n	Improvement	Normal finding	Unchanged	Worsening
Moderate	67	10	41	15	1
Severe	68	27	8	33	
Total	135	37	49	48	1

prove. Eight of these showed normal findings at the end of 12-month rehabilitation period. Three children had mild and 24 children moderate CMI.

Generally, rehabilitation resulted in significant improvement of the children's motor development (Table 1). Data obtained by analysis of answers to the questionnaire on family strength are presented in Table 2. There were no statistically significant differences in answers to the questions on family strength between the two study groups of children with moderate and severe cerebral motor disabilities and their parents (Table 3).

## Discussion

The present study confirmed the need and efficacy of rehabilitation treatment in children with motor development abnormalities. The introduction of rehabilitation improved motor development in children with CMI. Results of a prospective study conducted at Department and Polyclinic of Pediatric Rehabilitation, Dr. Mladen Stojanović University Hospital in Zagreb from 1966 till 1978 pointed to the benefits of rehabilitation procedures irrespective of its timing, since the progression of handicap was arrested in almost all cases, whereas leaving the handicap untreated always resulted in unfavorable se-

**TABLE 2**  
QUESTIONNAIRE ON FAMILY STRENGTH

	Statement	I disagree	I partially disagree	I neither agree no disagree	I partially agree	I fully agree	N
1	We can express our feelings	3	3	6	47	76	135
2	We are frequently worried about many issues	3	13	15	42	62	135
3	We do believe and trust each other	5	4	13	40	73	135
4	We face the same problems over and over	27	26	29	33	20	135
5	Family members are loyal to the family	2	8	6	30	89	135
6	It appears difficult to achieve what we tend to	36	31	19	35	14	135
7	We are critical toward each other	14	25	25	43	28	135
8	We as a family share similar values and beliefs	3	14	11	33	74	135
9	We as a family are doing well	3	3	9	39	81	135
10	Family members feel respect for each other	2	4	1	36	92	135
11	There is much conflict in our family	82	25	11	12	5	135
12	We are proud of our family	2	2	5	16	110	135
	N	182	158	150	406	724	1620

**TABLE 3**  
ANALYSIS OF DIFFERENCES IN ANSWERS TO FAMILY STRENGTH QUESTIONNAIRE BETWEEN TWO STUDY GROUPS (ARITHMETIC MEAN  $\pm$  STANDARD DEVIATION, MANN-WHITNEY TEST)

Family strength questionnaire	Cerebral motor disability			Mann-Whitney Z	Mann-Whitney p
	Moderate	Severe	Total		
We can express our feelings	4.40 $\pm$ 0.76	4.31 $\pm$ 0.97	4.36 $\pm$ 0.87	0.112	0.911
We are frequently worried about many issues	4.09 $\pm$ 1.01	4.09 $\pm$ 1.14	4.09 $\pm$ 1.08	–0.345	0.730
We do believe and trust each other	4.31 $\pm$ 0.94	4.26 $\pm$ 1.07	4.29 $\pm$ 1.01	–0.073	0.942
We face the same problems over and over	2.85 $\pm$ 1.36	3.03 $\pm$ 1.34	2.94 $\pm$ 1.35	–0.801	0.423
Family members are loyal to the family	4.55 $\pm$ 0.88	4.35 $\pm$ 0.99	4.45 $\pm$ 0.94	1.186	0.236
It appears difficult to achieve what we tend to	2.46 $\pm$ 1.27	2.93 $\pm$ 1.43	2.70 $\pm$ 1.37	–1.853	0.064
We are critical toward each other	3.25 $\pm$ 1.36	3.43 $\pm$ 1.20	3.34 $\pm$ 1.28	–0.594	0.552
We as a family share similar values and beliefs	4.24 $\pm$ 1.03	4.15 $\pm$ 1.18	4.19 $\pm$ 1.10	0.110	0.912
We as a family are doing well	4.52 $\pm$ 0.75	4.32 $\pm$ 1.00	4.42 $\pm$ 0.88	0.937	0.349
Family members feel respect for each other	4.67 $\pm$ 0.64	4.47 $\pm$ 0.91	4.57 $\pm$ 0.79	1.085	0.278
There is much conflict in our family	1.70 $\pm$ 1.15	1.82 $\pm$ 1.16	1.76 $\pm$ 1.15	–0.838	0.402
We are proud of our family	4.78 $\pm$ 0.57	4.63 $\pm$ 0.88	4.70 $\pm$ 0.74	0.482	0.630

quels. The study also indicated the introduction of extra-early rehabilitation to be fully justifiable, the early and extra-early rehabilitation to be highly successful, and the performance of rehabilitation procedures undertaken in delayed and late stages of the disorder to be quite limited<sup>14</sup>.

In their study, Shonkoff and Hauser-Cram clearly demonstrated the early intervention to be efficacious for developmental progress in many children with developmental abnormalities. In children with moderate abnormalities, inclusion in the rehabilitation program before the age of six months was associated with a significantly better outcome than the inclusion later in life<sup>15</sup>.

Family is the primary carer and protector of their children. All family members are engaged in managing difficulties and care for the one of them with a chronic disease<sup>16</sup>. Recently, ever more attention is being paid to the role of parents in the process of rehabilitation of children with chronic physical disabilities. This trend relies on two main arguments. First, rehabilitation transfer from rehabilitation centers to the children's daily living requires introduction of therapeutic activities in daily routine. Second argument is the impact that such an approach exerts upon parents. The parents taking active part in the child's rehabilitation have better insight into the child's abilities and can better adapt to the child's care, which in turn upgrades their self-confidence in terms of their competence while reducing the level of stress<sup>17</sup>.

One of our study hypotheses was that the birth of a child with CMI would lead to discordance and weakening of the family as a whole, by analogy with mothers to children with cerebral palsy, congenital cardiac errors or blindness, that are at a greater risk of marital troubles and divorce than mothers to healthy children<sup>18</sup>.

Parental reactions to stress generated by family problems related to the children's developmental and behavioral disorders have been extensively investigated. Oghi et al. assessed parental coping with excessive crying in infants with cerebral injuries and found excessive crying such as constant inconsolable crying to cause severe parental stress influencing the parent to child relationship<sup>19</sup>.

Some studies postulate that subjective burden upon the family is one of the major consequences that accompany cerebral injury in a family member. Continuous presence of the disabled family member can interfere with the family members' attempts at achieving psychological adjustment to the actual loss. The authors found a high incidence of initial depression, which decreased significantly at six months and remained stable thereafter<sup>20</sup>.

Trause and Kramer investigated the effect of preterm childbirth on the parents and their relationship. They found these parents to develop mutual sensibility with time, having become more focused on each other, whereas such a tendency that was also observed in parents to term infants diminished with time. With time, difficulties encountered while adjusting to the new situation were found to diminish in mothers while staying unchanged in fathers. The authors demonstrated the husband's support offered in the early period to be of great help to mothers in their process of adjustment. The greater the father's awareness of the mother's needs and feelings, the lower was the level of maternal difficulties in her adjustment to the disabled child<sup>21</sup>.

Parenthood is one of the most difficult tasks the humans have to face during life. The birth of the child is associated with deep changes in the parents' life. Parents as a rule will do everything they can to bring the child up in such a family atmosphere that will favor the child's growth and development. The birth of a child with CMI certainly poses great stress to the family. The parents are



expected to take care of their child, to make correct decisions and take appropriate steps in the child's upbringing, to include the child in the rehabilitation program, and to offer any kind of support and help to the child, while being fully aware of the fact that rehabilitation of a child with cerebral motor disabilities is a long-term, time consuming and painstaking process in which family plays a major role.

In our study, the questionnaire on family strength was filled out by mothers, therefore their opinion on their families and on their perception of family strength is discussed. Research of mother's perception of family strength according to family strength questionnaire in population of mothers of healthy children were not found in literature so comparison could not be made. The study hypothesis was that mothers to children with se-

vere forms of CMI would perceive their family strength differently from mothers to children with moderate forms of this disorder. However, study results showed no significant differences in the values obtained by the family strength questionnaire, indicating that there was no statistically significant difference between the two groups in their coping with stressors. It is postulated that the family crisis induced by the birth of a child with risk symptoms must have brought the parents closer and reinforced the family as a whole, irrespective of the severity of the child's clinical picture.

Similar data have also been reported from other studies, demonstrating that families with children suffering from chronic diseases are exposed to higher stressors than control groups, however, it should be noted that the former need not be less functional than the latter<sup>16</sup>.

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## OBITELJ I DIJETE S OŠTEĆENJEM SREDIŠNJEG ŽIVČANOG SUSTAVA

### SAŽETAK

Cilj studije bio je ispitati da li majke djece s teškim oblikom cerebralnih poremetnji kretanja drugačije doživljavaju jačinu svoje obitelji u usporedbi s majkama djece sa srednje teškim oblikom cerebralnih poremetnji kretanja. Ispitivanje je obuhvatio 135-ero djece s cerebralnim poremetnjama kretanja. Djeca su bila podijeljena u dvije grupe prema težini kliničke slike a njihov razvoj je praćen kroz godinu dana. Tijek rehabilitacije procjenjivan je metodom funkcionalne evakuacije lokomotornog sustava. Nakon 12 mjeseci s majkama je proveden strukturirani intervju. Majke su ispunile upitnik o obiteljskoj jačini, koji se sastojao od 12 pitanja o tome kako one doživljavaju jačinu svoje obitelji. Studija je potvrdila potrebu i učinkovitost rehabilitacije u djece s cerebralnim poremetnjama kretanja. Ispitivanje nije pokazalo značajnu razliku u rezultatima dobijenim upitnikom o jačini obitelji, što upućuje na to da između te dvije grupe nema značajne razlike u nošenju sa stresnim situacijama. Možemo pretpostaviti da je krizna situacija u obitelji inducirana rođenjem djeteta sa simptomima rizika dovela do uzajamnog zbližavanja roditelja i ojačavanja obitelji kao cijeline, bez obzira na težinu kliničke slike djeteta.

### **Appendix 1. Questionnaire on family strength**

1. We can express our feelings
2. We are frequently worried about many issues
3. We do believe and trust each other
4. We face the same problems over and over
5. Family members are loyal to the family
6. It appears difficult to achieve what we tend to
7. We are critical toward each other
8. We as a family share similar values and beliefs
9. We as a family are doing well
10. Family members feel respect for each other
11. There is much conflict in our family
12. We are proud of our family